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## Comparing Neonatal Morbidity and Mortality Estimates across Specialty in Periviable Counseling

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### Abstract

**Objective**—To describe and compare estimates of neonatal morbidity and mortality communicated by neonatologists and obstetricians in simulated periviable counseling encounters.

**Methods**—A simulation-based study of 16 obstetricians (OBs) and 15 neonatologists counseling standardized patients portraying pregnant women with ruptured membranes at 23 weeks gestation. Two investigators tabulated all instances of numerically-described risk estimates across individuals and by specialty.

**Results**—Overall, 12/15 (80%) neonatologists utilized numeric estimates of survival; 6/16 (38%) OBs did. OBs frequently deferred the discussion of “exact numbers” to neonatologists. The twelve neonatologists provided 13 unique numeric estimates, ranging from 3% to 50% survival. Half of those neonatologists provided 2-3 different estimates in a single encounter. By comparison, six OBs provided 4 unique survival estimates (“50%”, “30-40%”, “1/3-1/2”, “<10%”). Only 2/15 (13%) neonatologists provided numeric estimates of survival without impairment. None of the neonatologists used the term ‘intact’ survival, while 5 OBs did. Three neonatologists gave numeric estimates of long-term disability and one OB did.

**Conclusion**—We found substantial variation in estimates and noteworthy omissions of discussions related to long-term morbidity. Across specialties, we noted inconsistencies in the use and meaning of terms like ‘intact survival.’ More tools and training are needed to improve the quality and consistency of periviable risk-communication.

### Keywords

Doctor-patient communication; Extreme prematurity; Periviability; Risk communication

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Declaration of Interest

The authors report no financial conflict of interest.

## Introduction

Periviable neonates—born between 22-25 weeks gestational age—bear the greatest burden of infant mortality and morbidity. As many as half do not survive; and among those that do survive, two-thirds suffer moderate to severe neurological disability.[1-4] Physicians must counsel families about diagnoses that threaten delivery, and the prognosis of mortality and morbidity associated with extreme prematurity, in order to help them make resuscitation decisions and delivery management plans. In doing so, physicians must relay a substantial amount of new and unfamiliar terminology and numeric data. There is also marked uncertainty surrounding physicians' ability to prognosticate for any given patient. This makes periviability counseling a critically important, yet particularly challenging, area for risk communication.

While previous studies have considered the role of neonatologists in counseling families about resuscitation and extreme prematurity,[5-9] none to-date has specifically explored communication with families regarding risk estimates (e.g., probabilities, frequencies). Additionally, given the multispecialty nature of periviable care, it is also important to consider the role of other providers, such as obstetricians, in communicating risks to patients presenting with periviable pregnancy complications. While several studies have attempted to compare and contrast knowledge and attitudes regarding prematurity outcomes across specialties,[10, 11] none have looked specifically at what numeric risk physicians communicate to patients across specialties. In order to address gaps in knowledge about how neonatologists and obstetricians would communicate risk to the same patient, we conducted a comparative simulation study. We designed a scenario in which we could observe the variation in communication content across providers and specialty as well as the range of estimates of neonatal morbidity and mortality provided during periviable counseling encounters.

## Methods

With approval from the Indiana University Institutional Review Board, we conducted an exploratory single-center simulation study. The case, developed by a multi-disciplinary team of physicians, including obstetricians, neonatologists and maternal fetal medicine physicians, depicted a 31 year-old woman presenting with preterm premature rupture of membranes (PPROM) at 23 weeks gestational age. The clinical components of the simulation were refined in a series of pre-tests with 3 physician volunteers. We trained SPs to play the patient role based on detailed symptom and psychosocial profiles. Consistent with previous simulation work,[12] the actresses received more than 10 hours of training and feedback to ensure standardization. This training included 'rules of engagement' which basically required that the SP not speak nor interrupt the study physicians unless they asked questions to engage them in conversation. The exceptions to this rule were scripted prompts that the SPs were trained to deliver to ensure that particular management strategies were discussed in each encounter. Specifically, the actresses were trained to prompt study participants to discuss mode of delivery options, steroids, and palliation if the physician did not address these topics by the close of the encounter. Furthermore, the SPs were instructed to seek out a recommendation whenever multiple management options were discussed.

## Study Population

We recruited faculty and fellows from the Indiana University School of Medicine Department of Obstetrics and Gynecology (OB/GYN) divisions of General Obstetrics and Gynecology and Maternal Fetal Medicine and from the division of Neonatology at Riley Hospital for Children through in-person presentations at faculty meetings; e-mails to departmental distribution lists; and calls or visits to individual physicians' offices. OB/GYNs practicing gynecology-only as generalists or subspecialists were excluded from eligibility; likewise, obstetricians and neonatologists who participated in case development or pilot testing were excluded. In qualitative studies, thematic saturation is customarily reached with 10-15 participants drawn from relatively homogeneous populations.[13] Therefore, our target for recruitment was 16 neonatologists and 16 OB/GYNs among 45 eligible neonatologists and 37 eligible OB/GYNs.

Study participation took 2 hours and included completion of two simulation encounters; completion of a self-administered demographic survey; and a debriefing interview. Physicians were initially informed that the purpose of the study was to compare obstetricians' and neonatologists' counseling practices regarding delivery and resuscitation decisions for extremely premature infants. They were instructed to counsel each patient as they normally would in their everyday practice. During the debrief interview, physicians were asked to provide additional insight into their management goals and treatment plans for each patient; to discuss the role they felt a physician should assume in periviable decision-making; and comment on patient factors that affect their periviable counseling. Study participants received \$100 compensation.

## Data Analyses

We video-recorded each SP encounter, then transcribed the audio-recordings verbatim. For the purpose of this analysis, only the first of the two encounters was analyzed to avoid potential order or anchoring effects. Content analyses were conducted by 2 investigators (BTE and JP), who identified and tabulated all instances of numerically described risk estimates (e.g. probabilities, frequencies) of neonatal mortality, which included: any mention of the likelihood of death or survival; short-term morbidity, the likelihood of complications in the immediate postnatal period or during the course of the neonatal intensive care unit stay; and long-term morbidity, which included any mention of disability or impairment—or conversely, survival without impairment—extending beyond hospitalization into childhood and adulthood. After an initial review of the transcripts, the codes: 'survival', 'intact survival' and 'long-term disability', were identified as capturing almost all of the relevant content. An additional code, 'OB defers' was also created based on an observed pattern of obstetricians deferring conversation about neonatal prognosis to neonatologists. The two investigators then independently applied the four codes to the transcripts. All discrepancies were resolved by consensus. We utilized NVivo 10, a software program that facilitates qualitative analysis, to code and analyze the data.

## Results

Our study population was made up of 15 out of 45 eligible neonatologists (33%) and 16 out of 37 eligible obstetricians (43%). Table 1 describes their characteristics. The average age of the physicians was 44, and they had been in practice, on average, for 12 years. Most physicians were white women who were married and had children of their own. Our findings are summarized in Table 2. We provide both the content coding frequencies and sample quotes to illustrate the content of each category.

Overall, 12/15 (80%) neonatologists utilized numeric estimates of survival; whereas, only 6/16 (38%) OBs did. Half of the OBs (8/16) deferred the discussion of “exact numbers” to neonatologists, with comments like,

I'd like [the neonatologists] to come and talk to you just because they can give you the exact numbers [OB 16]

[The neonatologists] actually have a better handle of all the statistics...As I said, the most important people are going to be the neonatologist or the baby doctors, and so we will have someone from the nursery come and talk to you about all the statistics that they have and their numbers. [OB 5]

Interestingly, among the 12 neonatologists, all of whom received the same case description, 13 unique numeric estimates were communicated to the SPs. These estimates ranged from 3% to 50% survival. As well, half the neonatologists (6/12) provided 2-3 different estimates in a single encounter. For example, one neonatologist described the probability of survival as follows:

If you look down the road, if 1 in 3 or 4 babies survive this. . . so one-third chance, and in your case, I should say maybe closer to 40% chance, a little better than 1 in 3, chance that she will survive. [NEO 11]

Similarly, the 6 OBs who communicated numeric estimates provided 4 unique survival estimates (“50%”, “30-40%”, “1/3-1/2”, “<10%”). It is also noteworthy that only 2/15 (13%) neonatologists provided numeric estimates of survival without impairment. In addition, only 3 neonatologists and 1 OB gave numeric estimates of long-term disability, explaining:

Of those babies who survive, at least half will have some significant permanent impairment, which could affect the way they can walk or sit, their ability to run or play a sport, they may be slow or very slow in their ability to learn. [NEO 11]

And the chance for a long-term disability is probably going to be somewhere in the range of 80-85 %. [OB 3]

Notably, none of the neonatologists used the term ‘intact’ survival to describe survival without significant neurodevelopmental impairment, whereas 5 OBs did. This difference was observed in the following quotes—one from a neonatologist, the other from an obstetrician:

So when we take that one kid and they do survive they have significant impairments...you know that they're able to keep up with the other kids when they

enter school is probably in the low one to two percent. So one in a hundred, one in fifty. [NEO 5]

To give you an idea, probably less than 10 percent of babies born at 23 weeks are going to survive, and perhaps 10 percent of that will have an intact survival or normal wellbeing. [OB 4]

Not only did obstetricians and neonatologists utilize the term ‘intact’ survival differently, but what obstetricians seemed to *mean* or attempted to convey by ‘intact’ was “normal,” rather than “without significant impairment” which was the language utilized by neonatologists. For example, an obstetrician described ‘intact’ survival as:

And then there are two types of survival. There is, okay, the baby's alive, survives, you know, has a heartbeat and is breathing, but then there's what we term intact survival and so that would be a baby who survives intact with no problems. So, no delays developmentally, physical aspects of the baby's development... that would mean when he is 6, he's running through the backyard, kicking the ball. When he's 13, he's playing baseball or football and doing just fine and getting As and Bs in school and not having any problems. [OB-16]

## Discussion

In standardized periviable counseling encounters, neonatologists utilized numeric descriptions of risk more readily than OBs. Though OBs frequently deferred discussions of risk to the expertise of neonatologists, we found substantial variation in the actual point estimates provided by neonatologists and noteworthy omissions of discussions related to long-term morbidity. The terminology and meaning of ‘intact survival’ vs ‘survival without impairment’ were also used differently across specialties.

Neonatologists provided highly variable estimates of mortality and morbidity. We do not believe that this reflects a particular knowledge deficiency on the part of the providers, but rather, the difficulty inherent in the task of offering precise survival estimates in a setting of substantial uncertainty. Despite several studies that have attempted to refine our understanding of predictors of neonatal survival and improve prognostic capabilities,[3, 14-17] there still remains a great deal of uncertainty about prognostication in the periviable period. Whatever its etiology, survival rates were given inconsistently and this variation is concerning, given the importance that physicians place on using the best clinical evidence to guide decision-making.[18] One would hope that physicians would make clinical decisions and recommendations based upon shared professional standards and understanding of morbidity and mortality, and that patients would receive more uniform guidance based on the available evidence. To mitigate the challenges physicians face with risk communication, one author has developed a decision aid to assist in communication and informed patient decision-making.[19] The tool, which utilizes a card set of pictograms to visualize risks of survival and complications, represents an important first step toward improving the quality of counseling and decreasing variations in risk estimates. Such methods aim to improve patient comprehension, while simultaneously offering more standardized approaches to how

physicians present the data. Our findings suggest that further efforts to develop and test communication interventions and decision-support are needed.

Finally, the differences noted in the use of the term ‘intact’ survival and the meaning conveyed in its use are noteworthy. ‘Intact’ survival is understood by many practitioners to mean ‘without impairment’. However, in the context of neonatology, ‘intact’ survival may only indicate that the child does not meet criteria to be classified as ‘moderate to severe’ or ‘profoundly’ neurodevelopmentally impaired. Indeed, the study that informed the development of the NICHD’s birth outcomes calculator’s predictive model defined ‘moderate to severe’ neurodevelopmental impairment as a score of less than 70 on the Psychomotor Developmental Index (PDI) or the Mental Developmental Index (MDI) of the Bayley Scales of Infant Development; or moderate or severe cerebral palsy; or bilateral blindness; or bilateral deafness.[3, 20] This means that a child with blindness in one eye, deafness in one ear, a ‘PDI’ of 71, and only mild cerebral palsy would fall in the category of ‘survival without moderate to severe neurodevelopmental impairment’—a category that may be interpreted and/or communicated as ‘intact’ survival by the ill-informed clinician. In recent years, the term ‘intact survival’ has fallen out of favor within the neonatology community; likely due to concerns about its potential insensitivity, and also due to concerns about its potential for misinterpretation. ‘Survival without impairment’ is more readily used now, as a more nuanced, and perhaps more accurate, reflection of risk compared to ‘intact’ survival. Our findings suggest that advanced education is needed in the obstetrical community to ensure that appropriate expectations are set and accurate information is conveyed to patients across specialty.

Our study has notable limitations that must be considered in interpreting our findings. First and foremost, we do not account for components of risk communication forms other than numeric descriptions in this analysis. ‘Verbal descriptions’ of risk (e.g. “rare”, “low”, “very high”) were frequently utilized by physicians. However, due to the variability and inaccuracy in patients’ interpretations of verbal descriptions,[21] we opted to focus solely on quantified risk estimates for this initial exploratory study. There is also evidence to suggest that patients’ knowledge or recall, particularly of serious risks, is greater when numeric estimates are presented.[22] As a qualitative study performed at a single center with a relatively small number of study participants, our findings may not be representative or generalizable to other institutions or care settings. Indeed, qualitative methods are not intended to produce generalizable knowledge, but rather, to create new knowledge in content areas where little is known, and to generate hypotheses to inform future research. In addition, though simulation has been shown to replicate periviable counseling sessions with fidelity and verisimilitude,[23] it is possible that the behaviors observed in this study do not accurately reflect provider behavior in actual clinical settings. At the same time, if Hawthorne effects or social desirability create a bias, one might expect physicians to act more in line with what they believe to be ‘ideal’ communication behaviors; and thereby, bias our findings toward more favorable results than expected in actual clinical encounters.

Our findings have important implications for multispecialty care of periviable neonates. In this exploratory study, we found substantial variation in the mortality estimates provided to parents, and noteworthy omissions of discussions related to long-term morbidity. Moreover,



in discussions of long-term outcomes, neonatologists and obstetricians used different terminology and conveyed different meanings with jargon and phrases like ‘intact survival’ vs ‘survival without impairment.’ The potential disparity between information communicated by each specialty should be considered as a threat to quality and patient-centered care.[24] More tools and training are needed to improve the quality and consistency of periviable risk communication by providers. Future research and interventions should focus on reducing unwanted variation in communicating risk and improving physician to physician coordination and teamwork.

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**Table 1**

## Study Participant Characteristics

<b>N=31 (16 OB, 15 Neo)</b>		
	<b>Percentage</b>	<b>N</b>
Age	44.0 (mean)	30-69 (range)
Years in Practice	12.2 (mean)	1.5-40 (range)
Specialty		
OB/Gyn Generalist	38.7%	12
Maternal Fetal Medicine (MFM)	6.5%	2
MFM Fellow	6.5%	2
Neonatologist	29.0%	9
Neonatology Fellow	19.4%	6
Race/Ethnicity		
White	71.0%	22
Black	16.1%	5
Asian	9.7%	3
Biracial or multiracial	3.2%	1
Sex		
Male	29.0%	9
Female	71.0%	22
Marital Status		
Single, never married	6.5%	2
Married or partnered	83.9%	26
Divorced or separated	9.7%	3
Parenting (Y)	77.4%	24
Ever Sued(Y)	45.2%	14

**Table 2**

Summary of Results (OB N=16, Neo N=15)

Code	Frequency	Illustrative Quotations
OB Defers for 'Exact numbers'	OB: n=8	<i>And a lot of the numbers, honestly, I leave up to the NICU [OB 11] I'd like [the neonatologists] to come and talk to you just because they can give you the exact numbers [OB 16] [The neonatologists] actually have a better handle of all the statistics...As I said, the most important people are going to be the neonatologist or the baby doctors, and so we will have someone from the nursery come and talk to you about all the statistics that they have and their numbers. [OB 5]</i>
Survival	OB: n=6 Neo: n=12	<i>The likelihood of them surviving between 23 and 24 weeks might be right around 30-40% [OB 17] If you look down the road, if 1 in 3 or 4 babies survive this... so one-third chance, and in your case, I should say maybe closer to 40% chance, a little better than 1 in 3, chance that she will survive. [NEO 11]</i>
Intact Survival	OB: n=2 Neo: n=2	<i>To give you an idea, probably less than 10 percent of babies born at 23 weeks are going to survive, and perhaps 10 percent of that will have an intact survival or normal wellbeing. [OB 4] The survival without some pretty significant neurodevelopmental issues is low - it's only 10%, so only 1 out of 10 babies that are in her situation are going to survive without some serious neurologic problems...only a 10% chance of survival without some profound developmental problems intact [NEO 13] So when we take that one kid and they do survive they have significant impairments...you know they're able to keep up with the other kids when they enter school is probably in the low one to two percent. So one in a hundred, one in fifty. [NEO 5]</i>
Long-term Disability	OB: n=1 Neo: n=3	<i>And the chance for a long-term disability is probably going to be somewhere in the range of 80-85 %. [OB 3] Of those babies who survive, at least half will have some significant permanent impairment, which could affect the way they can walk or sit, their ability to run or play a sport, they may be slow or very slow in their ability to learn. [NEO 11]</i>